

Public Attitudes about Genetic Discrimination

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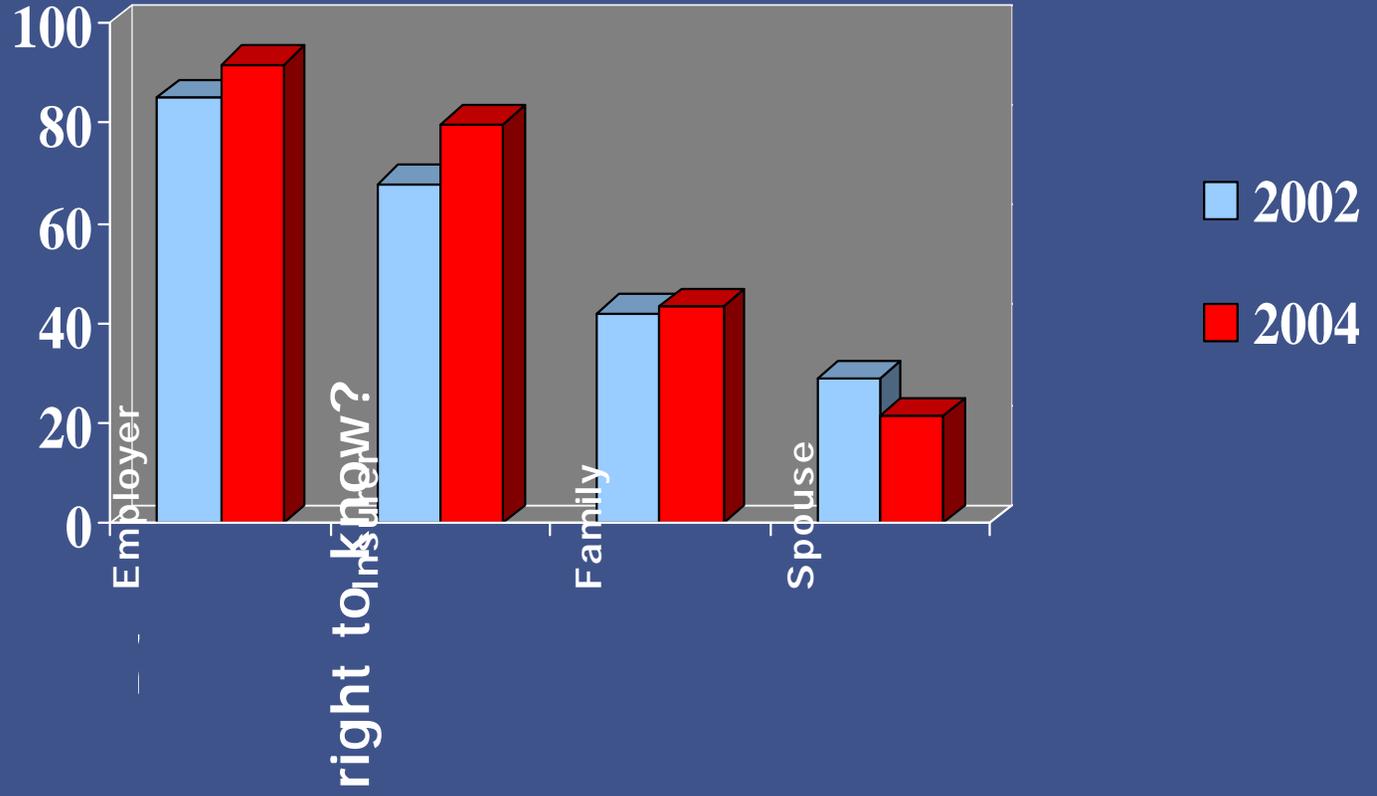
What does the public know, think and feel?



- December 2002 Survey of 1,211 citizens
- April 2003 21 Focus groups in 5 cities
- Fall 2003 >200 interviews
- April 2004 Survey of 4,834 citizens
- Summer 2004 Genetic Town Halls
 “on the road” and “on line”

increase

ON



[I]f they would test and find out, say, a woman is more susceptible to breast cancer, would they deny her insurance later in life?

Male from mixed group over age 55, CA



I think that's a real fear, that health insurance companies might say, if you don't have this test, or you don't have this procedure, we are not going to pay to take care of that ill child that you have.

Female evangelical group, CO

Elements of Deliberative Democracy

- *Broad* - Participation is broad and representative of the population to ensure all viewpoints
- *Informed* - The information provided must be balanced and accurate
- *Deliberative* - Provide an environment where participants have opportunity to evaluate their position based on the information and the different perspectives presented

Genetic Town Halls Making Every Voice Count

Sacramento, CA June 29

Seattle, WA July 1

Kalamzoo, MI July 19

Fort Worth, TX July 31

New York, NY Aug 2

Nashville, TN Aug 4

15 On-line Town Halls

3 meetings each



The Genetic Town Hall: Making Every Voice Count

- 9:00 Welcome and overview
- 9:20 Initial impressions - eFORUM questions
- 9:30 *Chosen Children: The Science of RGT*
- 9:40 *Chosen Children: The Ethics of RGT*, “table talk” - factors influencing setting limits, eFORUM voting
- 10:25 *Chosen Children: Safety and Accuracy*, group discussion, eFORM questions
- 10:55 *Chosen Children: Implications* , “table talk” - benefits and concerns, eFORM voting
- 11:40 Follow-up impressions - eFORUM questions
- 12:00 Community panel
- 12:30 Concluding remarks

Genetic Town Halls



What are some of the possible harms to individuals, families, or society of parent's ability to identify and select characteristics of their children?

- Discrimination*
- Loss of diversity
- Devaluing life
- Pressure on families to use the technology
- Commodification of children
- Psychological harm to child who doesn't measure up

#1 concern in Sacramento, New York; second in Seattle, Fort Worth, and Nashville



Will you have trouble getting a job because you have this gene that may cause cancer, whether or not you have cancer?”

Sacramento Town Hall participant

It [a gene mutation] is the ultimate preexisting condition.

Nashville Town Hall participant



If insurers paid for tests, they would want to know the results and that could affect what they would be willing to cover.

Fort Worth Town Hall

Discrimination will arise from genetic testing.

Nashville Town Hall

Conclusion

Americans overwhelmingly do not want insurers and employers to have access to genetic test results.

Concern about discrimination is upper most in the minds of citizens.

When legislative protections are enacted, efforts to inform the public of their rights will be needed to make sure that anxiety about discrimination does not adversely affect genetic testing decision making.



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